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Marginalisation of family life among patients in forensic psychiatry units

Marginalizacja życia rodzinnego wśród pacjentów oddziałów psychiatrii sądowej

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Abstract

Introduction and objective: The family is the most important social unit that builds society. It is credited with procreative, nurturing, and supportive roles. However, family life takes on particular importance when, as a result of illness, a person ceases to actively participate in it and becomes marginalised. The main aim of this study was to the phenomenon of marginalisation of family life in a group of long-term isolated patients incarcerated in forensic psychiatry units. Materials and methods: The study was conducted among 100 patients in forensic psychiatry wards. A self-administered survey questionnaire was used to gather data on the frequency of contact with relatives, plans for the future, and expectations about help and support after discharge from the hospital. Results: The most numerous group of patients (70%) were those who did not have regular contact with their families, of which 20% did not maintain any contact at all, and 50% rarely contacted their families. Regular contact with the family was reported by only 30% of patients. Most patients indicated that they expected help from their families after leaving the hospital (42%). Conclusions: Patients in forensic psychiatry units do not maintain regular contact with their families, which contributes to the marginalisation of family life. The phenomenon is mainly attributed to the stigmatisation of patients and their families by society.

Keywords: family, forensic psychiatry, schizophrenia

Streszczenie

Wprowadzenie i cel: Rodzina w ujęciu społecznym to najważniejsza jednostka społeczna, która buduje społeczeństwo. Przypisuje się jej cechy prokreacyjne, wychowawcze i wsparciowe. Życie rodzinne nabiera jednak szczególnego znaczenia, gdy na skutek choroby człowiek przestaje w niej aktywnie uczestniczyć i jest spychany na jej margines. Głównym celem pracy było opisanie zjawiska marginalizacji życia rodzinnego w grupie pacjentów długotrwale izolowanych osadzonych w oddziale psychiatrii sądowej. Materiał i metody: Badanie przeprowadzono wśród pacjentów oddziałów psychiatrii sądowej (100 osób). Wykorzystano autorski kwestionariusz ankiety, w której pytano o częstotliwość kontaktów z bliskimi, plany na przyszłość oraz oczekiwania dotyczące pomocy i wsparcia po wyjściu ze szpitala. Wyniki: Najliczniejszą grupę pacjentów – 70% – stanowiły osoby, które nie utrzymywały regularnego kontaktu z rodziną, w tym 20% w ogóle nie utrzymywało tego kontaktu, a 50% kontaktowało się z nią rzadko. Regularny kontakt z rodziną utrzymywało 30% pacjentów. Najwięcej pacjentów wskazało, że po opuszczeniu szpitala oczekuje pomocy od członków rodziny (42%). Wnioski: Pacjenci oddziałów psychiatrii sądowej nie utrzymują stałego kontaktu z rodziną, co prowadzi do marginalizacji życia rodzinnego. Przyczyny tego zjawiska wynikają głównie ze stygmatyzacji pacjentów i ich rodzin przez społeczeństwo. Identyfikacja doświadczeń pacjentów oddziałów psychiatrii sądowej i ich opiekunów związanych z barierami w radzeniu sobie z chorobą psychiczną jest niezbędna do opracowania programu wsparcia, który pomoże im przezwyciężyć te wyzwania i umożliwi przygotowanie się do roli pełnoprawnych członków rodziny i radzenie sobie z chorobą.

Słowa kluczowe: rodzina, psychiatria sądowa, schizofrenia

INTRODUCTION

amily life has been consistently associated, across generations, with love, support, warmth, and a shared space with people who are important and valuable to us, those we can rely on and expect support when needed (Piotrowska, 2012). The family, in such an approach, is a circle of individuals to whom one can always turn for help and receive it, precisely because of the connections and relationships. The conviction of a certain obligation and a sense of belonging and security that each member of the family community has towards their relatives gives the family its most important meaning (Chuchra, 2009). However, family life takes on particular significance when, as a result of illness, a person ceases to participate actively in it and, because of his or her disability, is relegated to its margins (Piotrowska, 2012).

Mental illness faced by patients in forensic psychiatry departments limits their participation in various life activities just like any other chronic condition (Piotrowska, 2012). The patient's seclusion in an inpatient facility, such as a hospital, exacerbates his or her disability and postpones the chance to participate in his or her current life. These changes depend on many factors, including the course of the disease, the intellectual level of the patient, access to and awareness of treatment options, as well as the family situation and relationships within the family (Chuchra, 2009; Piotrowska, 2012). Maintaining and nurturing family relationships takes on particular importance for patients in forensic psychiatry units. Long-term compulsory hospitalisation is a challenging period in the patient's life and promotes the disruption of the structure and function of the family in its fundamental aspects (Chuchra, 2009; Wong et al., 2018).

The analysis of the impact of mental illness on the family usually takes two directions: the influence of the family on the ill individual and the effects of the illness on the family (Piotrowska, 2012; Wong et al., 2018). In the latter case, it is primarily examined how the family copes with the situation and what changes and consequences the illness brings to the family dynamic (Chuchra, 2009). The way the family functions when one of its members is ill depends mainly on who the ill individual is and on the nature of their illness. The greatest changes in the family are caused by chronic illnesses, which undoubtedly includes schizophrenia (Wong et al., 2018).

Scientific interest in the families of patients with schizophrenia has a long history. In the 1940s, the family was considered the main factor responsible for the development of the disease. Blaming the family was later replaced by the notion that families contributed to relapses (Chuchra, 2009). Theories of the pathogenesis of schizophrenia that are currently accepted point to a genetic load that may cause feelings of guilt in the parents of the person with the illness. Over time, it has become clear that the material, emotional, and social consequences of the illness are borne by the family, and the responsibility for caring for the patient has been termed the "family burden" (Chuchra, 2009).

The presence of mental illness, along with the resulting emotional and social maladjustment of the patient, causes a change in family functioning. As a result of these changes, a profound reorganisation of the family takes place as it seeks to adapt to the new situation and maintain proper functioning (Wong et al., 2018). The family, as a dynamic system whose members are in constant interactions, can either exacerbate or alleviate symptoms, thereby modifying the course and prognosis of mental illness. Moreover, knowledge and understanding of what happens in the family of a person with schizophrenia have become a prerequisite for implementing the postulates of community psychiatry (Chuchra, 2009; Wong et al., 2018).

A person with mental illness, often perceived as the "other" in society, is still insufficiently understood by those around them. The reasons for this phenomenon are multifactorial, including a low level of knowledge about mental disorders in the population, societal prejudice against mentally ill individuals, and overt discrimination (Babicki et al., 2018). It is not uncommon for individuals who have once entered this role to remain mentally ill throughout their lives. Behaviours that deviate from accepted norms trigger mechanisms to bring the individual under control, such as compulsory treatment. The stigmatisation of the illness and the ill person causes that for many years the family is the last refuge for the mentally ill individual, constituting a group in which they can still function and be tolerated (Babić et al., 2017).

It is estimated that among patients in forensic psychiatry wards, about 15-20% are considered to have a difficult prognosis, the so-called long-stay patients, remaining hospitalised in forensic wards for more than five years, and usually much longer (Hare Duke et al., 2018). Patients separated from their natural environment, family, and social life, due to the lack of contact with their loved ones for a long period, are particularly vulnerable to loneliness and rejection (Babicki et al., 2018; Babić et al., 2017; Hare Duke et al., 2018). This phenomenon became a source of inspiration to undertake research in this area. The current study aimed to explore the phenomenon of marginalisation from family life among a group of long-term isolated patients detained in forensic psychiatry units based on an assessment of the frequency of contact with the family members, their attitude toward their detention, and their plans for the future.

MATERIALS AND METHODS

The study was conducted at the State Hospital for the Nervously and Mentally Ill in Rybnik, specifically in the forensic psychiatry wards, between September and October 2019. Before the start of the study, approval to conduct the study was obtained from the Director of the Hospital. The study involved 100 people undergoing the so-called judicial detention (16 women and 84 men). All patients participating in the study had a diagnosis of schizophrenia. The characteristics of the study group are presented in Tab. 1.

Variable	T-4-1(0/)	S			
variable	Total (<i>n</i> ; %)	Women (<i>n</i> ; %)	Men (<i>n</i> ; %)	<i>p</i> -value	
Age					
20–30	10; 10%	2; 12.5%	8; 9.5%	0.88*	
31–40	39; 39%	5; 31.2%	34; 40.5%		
41–50	20; 20%	3; 18.8%	16; 19.0%		
>50	31;31%	6; 37.5%	26; 31.0%		
Marital status					
Married	25%	4; 25.0%	21; 25.0%	<0.005*	
Divorced	55%	2; 12.5%	53; 63.1%		
Unmarried	12%	8; 50.0%	4; 4.8%		
Widowed	8%	2; 12.5%	6; 7.1%		
Education				•	
Primary education	15; 15%	1; 6.3%	14; 16.7%		
Lower secondary education	7;7%	3; 18.7%	4; 4.8%		
Vocational education	36; 36%	4; 25.0%	32; 38.1%	0.14*	
Secondary education	32; 32%	5; 31.3%	27; 32.1%		
Higher education	10; 10%	3; 18.7%	7; 8.3%		
Duration of patient detention in a close	ed psychiatric unit			•	
<6 months	32; 32%	2; 12.5%	30; 35.7%		
6–12 months	12; 12%	2; 12.5%	10; 11.9%	0.02*	
13–24 months	26; 26%	3; 18.7%	23; 27.4%		
25–36 months	10; 10%	5; 31.3%	5; 6%	\neg	
>36 months	20; 20%		16; 19.0%		
Employment relationship before hospi	talisation	· · · · · · · · · · · · · · · · · · ·		,	
Employed	45; 45%	6; 37.5%	39; 46.4%	0.5*	
Unemployed	55; 55%	10; 62.5%	45; 53.6%	0.5*	
* χ^2 test.	•	· · · · · · · · · · · · · · · · · · ·		•	

Tab. 1. Characteristics of the study group

The most numerous group consisted of individuals between 31 and 40 years old (39%), while the least numerous group included respondents between 20 and 30 years old (10%). The vast majority of respondents were unmarried (75%). Most respondents had vocational (36%) or secondary (32%) education, and only 10% of respondents had higher education qualifications. Furthermore, 55% of the respondents did not have a job before starting their compulsory hospitalisation in the closed psychiatric ward. The length of patients' stay in the forensic psychiatry department varied. The largest number of respondents stayed in the department for up to six months (32%), and a similar number of respondents had a stay of over three years in the department (30%).

The main criteria for inclusion in the study were as follows: the status of a patient in the Forensic Psychiatry Unit of the State Hospital for the Nervously and Mentally Ill in Rybnik, a diagnosis of schizophrenia, consent to participate in the study, and maintenance of basic competence in cognitive functioning. Patients in the acute phase of the illness and those temporarily present in the department for forensic psychiatric observation were excluded from the study.

All patients participating in the study were individuals under the so-called judicial detention, a protective measure for mentally ill offenders.

The research questionnaire was completed by 100 patients, encompassing all those who were in the forensic psychiatry wards at the time of the study and met the inclusion criteria. The respondents, after being acquainted with the course and purpose of the study, gave their independent and informed consent to participate in the study.

In accordance with Polish law, this study was not a medical experiment, so it did not require the approval of the Bioethics Committee (Act of 5 December 1996 on the Professions of Physician and Dentist – Journal of Laws of 2019, item 537). Nevertheless, all research standards were upheld, and the study adhered to the provisions of the Declaration of Helsinki.

A self-administered questionnaire was used, consisting of 30 questions. The metric part asked about the gender, age, length of stay in the ward, education, and marital status, while the main section asked about the frequency of contact with relatives, plans for the future, and expectations for help and support following discharge from the hospital.

Statistical analysis was performed using Statistica 13.3 PL software (StatSoft, Kraków, Poland). The normality of data distributions was assessed by the Shapiro–Wilk test. The χ^2 test was applied to test the significance of differences. Nonparametric correlation tests (Gamma and V Cramér) were

Question	Answer	Total (<i>n</i> ; %)	20-30 years	31–40 years	41-50 years	>50 years	<i>p</i> -value
To whom will you turn for help after leaving the psychiatric hospital?	Family	42; 42%	3 (30%)	13 (33.3%)	3 (15%)	22 (71%)	p = 0.00002*
	Friends and colleagues	15; 15%	2 (20%)	9 (23.1%)	2 (10%)	2 (6.5%)	
	Social assistance centre	30; 30%	2 (20%)	8 (20.5%)	14 (70%)	7 (22.5%)	
	I do not need any help	13; 13%	3 (30%)	9 (23.1%)	1 (5%)	0	
Do you keep in touch with family or relatives?	Yes – often	30; 30%	5 (50%)	10 (25.7%)	8 (40%)	7 (22.6%)	
	Yes — very rarely	50; 50%	2 (20%)	24 (61.5%)	10 (50%)	14 (45.2%)	p < 0.05*
	No one visits me	20; 20%	3 (30%)	5 (12.8%)	2 (10%)	10 (32.2%)	
* χ^2 test.							

Tab. 2. Frequency of contact between patients and family and the extent of their expectations after leaving the hospital

Question	Answer	n; %
	Yes	75; 75%
Does your family take sufficient care of you?	No	19; 19%
	Don't know	6; 6%
	Yes, regularly	12; 12%
Do you use home leave?	Yes, very rarely	10; 10%
	No	78; 78%
What are considered for the factors 2	Continuation of psychiatric treatment at a Mental Health Clinic	40; 40%
	Rebuilding family relationships	13; 13%
What are your plans for the future?	Finding a job	37; 37%
	I have no plans	10; 10%
Do you know the reason for your treatment in a closed	Yes	80; 80%
psychiatric unit?	No	20; 20%
In your opinion, is the judgment of the court with an order	Yes	60; 60%
for treatment in a closed psychiatric unit just to the offence committed?	No	40; 40%

Tab. 3. Respondents' opinions on their relationship with family, future, and justifiability of staying in a closed psychiatric unit

used in the analysis of associations between the studied variables. Results for which p < 0.05 were considered statistically significant.

RESULTS

As many as 50% of the patients reported having very little contact with their families, only 30% of the patients had regular contact with their loved ones, while 20% of the patients had no contact at all. The youngest patients in the unit (between 20 and 30 years of age) were the most frequently contacted by their families. As many as 32.2% of the patients over 50 years old had no contact with their relatives. Most patients (42%) indicated that after leaving the hospital they expected support from their families. This was the most frequent response given by individuals over 50 years of age. As many as 70% of patients aged 41–50 planned to turn to the Social Assistance Centre for help. Thirteen percent reported that they did not need any help and could lead an independent life after leaving the ward. The results are presented in Tab. 2.

Seventy-five percent of the respondents agreed that they were sufficiently cared for by their families. Only one in five respondents was dissatisfied with the care provided by their family. Passes allowing to leave the ward under the supervision of a loved one were used by just a small percentage of patients – only 22% of them used these passes regularly or occasionally. The vast majority of patients did not use this option. As many as 10% of patients undergoing judicial detention were unable to specify their plans for their future. Most patients (40%) hoped to continue treatment in an outpatient setting. A large group of patients (37%) aimed to find a job after completing treatment, and 13% wished to rebuild family ties. Most patients (80%) were aware of the reasons for their placement in a closed psychiatric ward, and only 20% of the respondents did not know the reason for the judicial detention. Despite this, as many as 40% of the patients disagreed with the court's decision and the forced placement in the forensic psychiatry unit. The results are presented in Tab. 3.

DISCUSSION

Care in the patient's natural environment, alongside pharmacotherapy and psychoeducation, is a key element in the treatment of patients with mental disorders. Many specialists believe that the patient's family or guardians should always be included in the planning of treatment strategies and involved in the psychoeducation and therapy process. Families involved in the therapeutic process play a crucial role in ensuring adherence to therapy, relapse prevention, and

re-education of patients in social skills. They are a significant pillar in the treatment system for people with schizophrenia (Chądzyńska et al., 2008). However, our study of patients undergoing judicial detention shows that only a small group of patients can count on family support.

According to current laws and standards of practice, patients leaving psychiatric institutions are not subject to supervision by probation officers or social workers, so it is the responsibility of the patient's family to specifically supervise and assess the risk of reoffending. The care and supervision provided by loved ones are undoubtedly essential elements of ongoing treatment and therapy in a custodial setting (Chądzyńska et al., 2008; Pawełczak et al., 2014). Continuous contact with loved ones allows convicts to orient themselves in matters relevant to their family, and to share both struggles and joys. The family is the most frequently mentioned source from which they expect help and support. This is particularly noticeable among the oldest patients. However, the survey, clinical experience, and the author's observations indicate that families are often reluctant to visit mentally ill offenders, even though they have every right to do so. According to the hospital's regulations, visits are allowed every day at any time, excluding meal breaks and therapeutic activities. For patients, these moments of family interaction are described by patients as special and highly anticipated. It is, therefore, saddening to learn that during their stay in an inpatient facility, only some of the patients receive help from their loved ones and can count on their support after leaving the hospital.

In Sweden, extensive re-adaptation plans are implemented at the time of discharge to help forensic psychiatric patients return to society. Many of Sweden's forensic psychiatric facilities employ social workers who work with various social services to address patients' housing and support needs at discharge, and to ensure the patient's financial situation is managed (Noland et al., 2023).

Sweden, like other Nordic countries, has a comprehensive social welfare system. This fact makes it more important to examine what the living situation of this vulnerable group of people is like in various dimensions of well-being, using a broader perspective than just assessing re-conviction rates (Noland et al., 2023).

Challenges in the daily life of families with a member suffering from a mental illness limit their social circle and impoverish their cultural and social life (Pawełczak et al., 2014). The lack of shared leisure activities, the abandonment of organised leisure activities, and the avoidance of social gatherings isolate individual family members from one another and the whole family from the wider community. Although patients of forensic psychiatry units participating in our study expressed the need to rebuild family ties, this group appeared to be small. The respondents focused mainly on the need to continue treatment in a custodial setting and find employment, which is undoubtedly an important element of self-reliance in patients' life, but the low need for integration with family members may be of concern, especially considering that it is from the family that patients will need help and support after leaving the psychiatric facility.

The lack of support from the community is another factor that can influence the prolongation of judicial detention and increase the risk of institutionalisation. In forensic psychiatric opinions, both the court and experts pay attention to the relationship of the detainee with their family, as support from loved ones can facilitate the return to society and reduce the likelihood of committing a criminal act in the future (Pyrcak, 2011).

Thus, constant and regular contact with the outside world is an essential factor, not only in terms of reintegration into the family environment, but also a key factor in the decision to terminate treatment (Carrara and Ventura, 2018; Noland et al., 2023). Unfortunately, the number of patients benefiting from a temporary stay outside the institution (so-called passes) is very low, which prevents the achievement of some therapeutic goals and adversely affects the process of rehabilitation and treatment.

For the good social functioning of ill individuals and their families, the relationships with their surroundings, that is, with neighbours, relatives, acquaintances, friends, co-workers, superiors at work, and employees of institutions with which the families of the ill individual come into contact, play an essential role (Pawełczak et al., 2014; Pyrcak, 2011). The family of a mentally ill person often faces resentment from within the family itself and arouses fear in the public, especially among close family and neighbours, and even people who encounter the mentally ill in public. This unidentified resentment is a real and existing phenomenon. Fear of being disliked, treating the illness as an embarrassing matter, and uncertainty about the reactions of friends and acquaintances make the families of the mentally ill more lonely than the families of the physically ill (Pyrcak, 2011). This may by one of the reasons why families of forensic psychiatry patients are reluctant to take their loved ones on furloughs, or temporary stays outside the facility.

Undoubtedly, a temporary stay outside the facility allows the patient to revise his or her idea of the world by participating in family and social life. Therefore, giving passes to the patient seems to be the most advisable and valuable approach in the context of regaining the patient's social integration and preventing institutionalisation.

Moreover, the patient's enjoyment of a temporary stay outside the facility allows for a realistic assessment of the relationships between individual family members. Patients in forensic psychiatry wards often exhibit wishful thinking (an erroneous, usually overly optimistic idea of their relationships with their families), which was confirmed in a study conducted when, despite the lack of family presence in the patient's life, they still felt cared for and taken care of by their loved ones (Carrara and Ventura, 2018; Pyrcak, 2011).

This raises the question: why do families of patients hospitalised in forensic psychiatry units rarely visit their loved ones? What could be the reasons for such behaviour, and | 237 what factors influence it? An attempt to explain this phenomenon is presented below.

From the professional experience of the authors of this publication, it is clear that a major problem for families is the location of the psychiatric institution, which is often a long distance from their homes, making visits difficult and placing a strain on family and friends who wish to maintain contact. Moreover, many family members have experienced violence from a relative undergoing hospitalisation, which can instil a fear of repeat violence. The separation from a loved one, despite the tensions and stresses of confinement, can trigger the family to experience a kind of calm and reinforce their sense of security. Therefore, a return to the home environment under such circumstances may become impossible.

It should also be made clear that many myths and misconceptions about psychiatric wards still persist in society, some of which are associated with forensic psychiatric wards. This raises fears among families about being stigmatised by neighbours and friends, which is related both to the mental illness of their family member and the crime they may have committed (Evans, 2021).

Research (Evans, 2021; Khalil et al., 2022) shows that for every patient diagnosed with schizophrenia, there are about 10 individuals in their immediate circle directly affected by the consequences of the disease. This can lead to several negative outcomes, such as the deterioration of mutual relationships, difficulties in making necessary decisions related to providing care to the patient, and increased burden and stress related to the illness (Borowiecka-Kluza et al., 2013). The loss of health is a difficult experience, not only for the patient, but also for their family members, who are most often responsible for their care. The family is responsible for the material, emotional, and social consequences of the illness, which greatly affects the psychological well-being of its members (stress, depression, neurosis). The burden on the family is even greater when the illness is mental and, in addition, chronic (Borowiecka-Kluza et al., 2013).

However, the greatest burden is felt by caregivers on a subjective level. Caring for a chronically ill person, which requires commitment and sacrifices, is often associated with fatigue and functioning under constant stress, which can lead to the development of burnout syndrome with high levels of depressive and anxiety symptoms (Khalil et al., 2022).

There are research findings that clearly show that family members of individuals living with mental illness suffer from stress and stigma, and they find caring for a mentally ill family member difficult and highly burdensome (Alzahrani et al., 2017; Olawande et al., 2019). In addition, scientific studies have found that a major challenge for families of patients with mental disorders is their negative labelling, which is a very significant source of stress and leads to the discrimination and exclusion of caregivers from social life (Alzahrani et al., 2017; Chan, 2011; Reupert et al., 2021; Walke et al., 2018).

For this reason, to overcome the difficulties described above, researchers pay special attention to the need for the development of support programmes for patients and their families (Cleary et al., 2020; Hasan and Musleh, 2017; Wan and Wong, 2019; Wang et al., 2020).

Undoubtedly, combating the phenomenon of stigmatisation and discrimination of individuals affected by a mental disorder or illness and their families is becoming one of the key priorities in the field of mental health (Babicki et al., 2018).

The literature on the presence of the family in the process of treating patients in closed forensic psychiatric units is scarce and rarely raises the topic discussed in this study. Despite efforts to find similar studies (PubMed, Google Scholar, ResearchGate), no publications related to the issue of the study were found in the available literature.

A review of the available scientific publications does not provide conclusive evidence that therapeutic programmes aimed at strengthening or improving family ties are not used in forensic psychiatry departments, and that activities in this area are limited to educational and consultation activities (Cleary et al., 2020; Evans, 2021; Khalil et al., 2022; Olawande et al., 2019; Wan and Wong, 2019; Wang et al., 2020). While most publications indicate the significant need in this regard, no information on their use was found.

Despite the challenges in meeting the care needs of patients hospitalised in forensic psychiatry units, the lack of therapeutic programmes aimed at improving and strengthening family ties, as well as negative experiences arising from societal attitudes, it is important to emphasise that the role of the caregiver in the treatment process of a patient with schizophrenia has been confirmed in clinical practice, which proves that family support in the course of therapy and treatment is invaluable.

A limitation of the study was the lack of consideration of the clinical picture and severity of schizophrenia symptoms, especially the negative symptoms. Perhaps the clinical condition of the patients could explain the small percentage of patients who are visited by their family members, despite the high percentage of respondents who were satisfied with family care. Additionally, the survey was conducted in a forensic psychiatry department, which has the specificity of protective measures. The results can, therefore, only be replicated in forensic psychiatry wards and cannot be generalised to all psychiatric wards with long-stay mental patients.

CONCLUSIONS

Patients treated in forensic psychiatric wards maintain unsatisfactory contact with their families from a therapeutic perspective and rarely take leave, which marginalises them from family life and further hinders their process of social readaptation. Despite the lack of regular visits, patients feel well looked after by their closest relatives and expect support from them after leaving the ward. Identifying the experiences of forensic psychiatric ward patients and their carers regarding barriers to coping with mental illness is essential

to developing a support programme to help them overcome these challenges and enable them to prepare for their role as a full-fledged family members and manage their illness.

Conflict of interest

The authors do not report any financial or personal connections with other persons or organisations which might negatively affect the content of this publication and/or claim authorship rights to this publication.

Author contribution

Original concept of study: JF, MK. Collection, recording and/or compilation of data; analysis and interpretation of data; writing of manuscript: JF, MKG. Critical review of manuscript; final approval of manuscript: MK.

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